AGING WITH A DEVELOPMENTAL DISABILITY

2005 White House Conference on Aging
Listening Session Testimony
December 8, 2004
Chicago, Illinois

Alan R. Factor, PH.D.
Associate Director
Rehabilitation Research and Training Center on Aging with Developmental Disabilities
Department of Disability and Human Development
University of Illinois at Chicago

The Rehabilitation Research and Training Center on Aging with Developmental Disabilities is funded by the United States Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research, Cooperative Agreement #H133B031134. The contents of this document do not necessarily represent the policy of the U.S. Department of Education.

Good morning. My name is Alan Factor. I am associate director of the Rehabilitation Research and Training Center on Aging with Developmental Disabilities. Our center is housed in the Department of Disability and Human Development at the University of Illinois at Chicago. I am here this morning to request that the 2005 White House Conference on Aging address the needs of older adults with mental retardation and related developmental disabilities and their families.

The "graying" of the United States population also includes adults with MR/DD who are part of the large post-World War II baby boom generation. Like the general population, people with MR/DD are also experiencing increased life expectancy. The mean age at death for persons with MR/DD rose from 19 years during the 1930's to 66 years in 1993, an increase of 247% (Janicki, Dalton, Henderson & Davidson, 1999). There were an estimated 641,161 adults with MR/DD age 60 and older in the US in 2000. **We project this group will nearly double in size to 1.2 million by 2030 when the last of the baby boom generation reaches age 60** (Heller, T. & Factor, A., 2004).

It is also important to recognize that the majority (60%) of individuals with MR/DD live with their families (Fujiura, 2001), and in one quarter of these households the primary caregiver is age 60 or older (Fujiura, 1998). Over the next thirty years, there will be a considerable increase in the number of two-generation elderly families living together where parents age 80 plus are caring for an older son or daughter with a developmental disability. Most families will remain intact as long as possible due to choice or the lack of satisfactory alternatives, even though these arrangements are likely

to be compromised by the parents' health problems. Nationally, an estimated 75,000 families are currently on residential services waiting lists for their relative with MR/DD (Coucouvanis, K., Polister, B., Prouty, R. & Lakin, K.C., 2004).

The later life concerns of individuals with developmental disabilities are essentially the same as those of the general elderly population:

- Maintaining health and function through medical research and improved access to health care and health promotion activities (Davidson, P., Heller, T., Janicki, M.P., & Hyer, K., 2003)
- Developing more effective models of dementia care including group homes in the community (Janicki, M.P., Heller, T., Seltzer, G. & Hogg, J., 1996)
- The ability to age in place in the community by providing supports and services to caregivers as well as care receivers.
- Reducing disincentives to work such as the stringent asset and income limits for Medicaid eligibility.
- Meaningful retirement activities that enable the elderly to contribute to their communities.
- Ensuring elderly and disability-friendly communities by greater use of environmental modifications and assistive devices (Hamel, J., Lai, J. & Heller, T., 2002).

These common concerns and states' compliance with the Olmstead decision underscore the importance of aging and developmental disability collaboration at the national, state, and local levels. The infrastructure for collaboration already exists:

- The 1987 Developmental Disabilities Assistance and Bill of Rights amendments (P.L. 100-142) required state units on aging to serve on state developmental disabilities councils and the latter are required to comment on state aging agency annual plans (Janicki, 1991).
- The Older Americans Act: (1) allows states to fund supportive services for older adults with severe disabilities and to meet the unique needs (including permanency planning) of older individuals who provide uncompensated care for their adult children with disabilities (42USC3030d); (2) requires state units on aging to coordinate the nursing home ombudsman program with the protection and advocacy system for individuals with developmental disabilities (42USC3030g); (3) allows disabled, dependent adults under age 60 to be served at congregate meal sites if they attend with an eligible parent or caregiver (42USC Nutrition Program for the Elderly); enables the AoA to fund multidisciplinary gerontology centers with an emphasis on disabilities (USC3058g) (U.S. Code Online via WAIS.access.gpo.gov, 2004); and (5) encourages state units and area agencies on aging and state and community MR/DD agencies to jointly plan and develop services for older adults with MR/DD (Janicki, 1991).
- The Robert Wood Johnson Foundation Consumer Choice Initiative and federal systems change grants enabled state units on aging to incorporate the disability

community philosophy of self-determination and consumer direction in their services.

- The National Family Caregiver Support Program (NFCSP) funded demonstrations that served older families caring for adults with developmental disabilities. Successful outcomes in Illinois included aging network outreach to older families not receiving services, joint collaboration with local MR/DD agencies to meet their needs, and providing future planning training to older parents and adults with disabilities. The Arc's national demonstration project provided joint training and technical assistance to foster state aging and MR/DD service system collaboration.
- Our center's survey of state NFCSPs indicated that respite care for older parent caregivers was the program's greatest unmet need. Nearly half (46%) of the state units on aging also rated older parents care giving and future planning concerns as the most important staff training topic. (Factor, 2004).
- The Administration on Aging and the Center for Medicare and Medicaid Services have jointly funded 24 state units on aging to develop Aging and Disability Resource Centers as the single point of entry for all consumers, including individuals with developmental disabilities, seeking long term care services.

These factors make it critical that the 2005 White House Conference on Aging include the later life needs of older adults with developmental disabilities and their families in formulating national aging policy for the 21st century.

Thank you.

REFERENCES

Davidson, P. W., Heller, T., Janicki, M. P., Hyer, K. (2003). *The Tampa scientific conference on intellectual disability, aging, and health*. Chicago: RRTC on Aging with Developmental Disabilities, University of Illinois at Chicago.

Factor, A.R. (2004, April 15). *The NFCSP as a resource for families of individuals with developmental disabilities.* Presentation at the ASA/NCoA Joint Conference, San Francisco.

Fujiura, G. T. (2001). *Family demography: Emerging policy challenges*. Paper presented At the Invitational Research Symposium on Agoing with Developmental Disabilities: Promoting Healthy Aging, Family Support, and Age-Friendly Communities.

Fujiura, G.T. (1998). Demography of family households. *American Journal on MentalRetardation,103,* 225-235.

Hammel, J., Lai, J. & Heller, T. (2002). The impact of assistive technology and environmental interventions on function and living situation status for people who are aging with developmental disabilities. *Disability and Rehabilitation*. *24*(1-3), 93-105.

Heller, T., & Factor, A. (2004). *Older adults with developmental disabilities and their aging family caregivers.* Chicago: RRTC on Aging with Developmental

Disabilities, University of Illinois at Chicago.

Janicki, M. P., Heller, T., Seltzer, G., & Hogg, J. (1996). Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability. *Journal of Intellectual Disability Research, 40*, 374-382.

Janicki, M.P., Dalton, A.J., Henderson, C.M., & Davidson, P.W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation, 21*, 284-294.

Janicki, M.P. (1991). *Building the future: Planning and community development in aging and developmental disabilities.* Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities.

U.S. Administration on Aging. The Older Americans Act (USC42, Ch. 35). (December 4, 2004). U.S. Code On-line. Available: www.wais.access.gpo.gov.